Report on
2001 Wisconsin
Nursing Home Relocations

for People Who are Elderly or Have a Physical Disability

June 2003

Prepared by
Department of Health and Family Services
Division of Disability and Elder Services
Bureau of Aging and Long Term Care Resources

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Introduction

In 2001, some Community Options Program (COP) Waiver[1] funding that was no longer needed for the start-up of the Family Care pilot[2] was transferred from the Family Care program to the then Division of Supportive Living, Bureau of Aging and Long Term Care Resources (DSL/BALTCR). Rather than allocating this money among all counties, the Department of Health and Family Services (the Department), through DSL/BALTCR, made the funds available to counties on a person-specific basis to relocate people from nursing homes. Over the months that this funding was available (May 2001 through November 2001), DSL/BALTCR staff assisted 46 counties as they worked with 153 individuals who wished to leave a nursing home.

This report summarizes the characteristics of the 153 people who were part of this initiative. All relocations in this initiative were from skilled nursing facilities, not intermediate care facilities for mental retardation. Additional individuals were relocated during this time period, but only data on those who were part of this initiative are analyzed in this report.

The participants were from all of the COP target groups[3], but most of them were either elders with infirmities of aging or persons with physical disabilities. At the time of the initiative, persons relocated ranged in age from 20 to 93. Most of them relocated to their own homes or moved in with family members. Others moved to substitute care settings that are less restrictive than nursing homes. Six of the 153 participants were never relocated, although the county did extensive work to develop a relocation plan. At the time the data was gathered for this report, almost all of the 147 participants who did relocate remained in the community. Four had died, and five had returned to nursing homes.

The data used for this report were obtained from the Human Services Reporting System (HSRS), from Medicaid data and from the participants' case files. BALTCR has paper records for all 153 persons who were part of the relocation initiative. Some participants were not found in the HSRS database at the time the data was collected.[4] The HSRS information was supplemented from the paper files when possible. In the tables and figures that follow, participants are listed as "unknown" when information on them is not available.

[1] The Community Options Program provides a structure and funding for community-based long-term care services not covered by Wisconsin's Medicaid State Plan. One of the methods of funding COP services is through a number of federal home and community-based waivers designed for certain target groups. The COP Waiver is one of these federal waivers and is targeted to elders and persons with physical disabilities.
[2] Family Care is a long-term care model being piloted in Wisconsin. The model uses managed care funding concepts and person-centered, outcome-based care planning to ensure cost-effective use of resources.
[3] The COP target groups are: physical disability, developmental disability, elderly, serious and persistent mental illness, and substance abuse.
[4] Demographic data was collected early in the process of developing this report and may not have been available due to a lag in reporting by counties.

Because of the relatively short periods of time that some people had been receiving community-based services at the time the data was gathered, it is not advisable to draw firm conclusions about the success or cost effectiveness of nursing home relocations from this report. The tentative findings, however, are positive. Many people with complex medical and/or behavioral needs were relocated. In addition, more very old people (age 75 and over) were relocated than conventional wisdom might suggest would occur. Generally, public costs (combined Medicaid and community long-term support costs) for people in community placements were lower than or comparable to costs for the same people while in nursing home placements.

Demographics

Participants representing all COP target groups were involved in this initiative. The largest group was the elderly, at almost 63 percent. The next largest group was persons with physical disabilities, which makes up 32 percent of the relocation initiative population. Persons with developmental disabilities accounted for only two percent of participants.[5] The remaining three percent of participants had a serious mental illness, a substance abuse diagnosis or some other unspecified disability. This mix is to be expected since the funding that was available for this initiative was specifically for elders and person with physical disabilities. Most of the participants were over age 65, and most were women.

Table 1
Participants by Target Group (n=153)

Target Group	Number	Percent
Elderly	96	62.7%
Physical Disability	49	32.0%
Developmental Disability	3	2.0%
Substance Abuse/Other	4	2.6%
Serious & Persistent Mental Illness	1	0.7%

Table 2
Participants by Age (n=153)

Age	Number	Percent
18-24	2	1.3%
25-34	4	2.6%
34-44	7	4.6%
45-54	11	7.2%
55-64	29	19.0%
65-74	38	24.8%
75-84	41	26.8%
85 years and over	21	13.7%

[5] The funding available for this initiative was COP Waiver funding which is targeted to elders and person with physical disabilities who meet a nursing home level of care. Persons with primary disabilities other than frailties of aging or physical disability still must meet the nursing home level of care required for this waiver.

Table 3
Participants by Gender (n=153)

Gender	Number	Percent
Female	92	60%
Male	61	40%

Behind the numbers…

¤ The oldest person to benefit from nursing relocation funding was a 93-year-old man from Grant County. Considered exceptionally intelligent, he has had a disability all of his life since having polio at age two. He seems to have led an active life as a farmer and electrician, although he never married. At some point, he completed law school in two years and passed the bar exam. For the past several years, he has moved between home and nursing homes. Apparently, when he was home alone without any help, he did not eat well or take good care of himself and his health declined. He would become stable in the nursing home, go home, and deteriorate again. Even with the difficulties, he preferred to be in a home setting. Finally, funding became available to allow him to move to an adult family home where he can get the help that will keep him stable.

¤ The youngest person relocated was only 20. Severely injured in a car accident, he was in a coma and on a ventilator and tracheotomy for some time. After as much rehabilitation and therapy as professionals thought beneficial, he was placed in a nursing home. His family's home was inaccessible and his parents work during the day, so he couldn't go home without help. He was moved back home with his parents and sister to rebuild his life. In addition to needing help with all of his personal cares and just getting around, he needs help in adjusting to his future. Once very social, his friends no longer come around. Someone his age will be recruited to take him into the community to interesting places and events, so that he can begin to make friends once again. He is a hard worker and continues to challenge himself. He has already set goals of raising animals and eventually driving.

Participants were mostly white and non-Hispanic. This group made up a larger percentage of the participants in this initiative than they do among the COP/Waiver population (94 percent of the relocated participants compared to 86 percent of all COP/Waiver participants). The percentage of Hispanic participants is the same for both the relocation initiative participants and the COP/Waiver population. The small number and percentage of African American individuals among initiative participants is due in part to the lack of relocations from Milwaukee County. Only one person was relocated in Milwaukee County in 2001. However, Milwaukee County is a Family Care pilot county for elderly persons (defined in Milwaukee as persons over 60), which means that funds are available through the Family Care benefit for relocations of individuals in that group.

Table 4
Participants by Race/Ethnic Background (n=153)

Race/Ethnicity	Number	Percent
Caucasian	144	94.1%
African American	2	1.3%
Hispanic	2	1.3%
American Indian	3	2.0%
Asian/Pacific Islander	2	1.3%

Behind the numbers…

¤ An 81-year-old Hmong woman in Sheboygan County experienced a stroke and was discharged from the hospital to a nursing home. Funding was not available to help her family take her home, but she did not understand and felt abandoned. She speaks no English and was very fearful in the unfamiliar setting of a nursing home. She would not eat the food and would only eat traditional food her family brought. She became more and more apathetic and depressed, stopped walking, insisted her family stay with her, and remained in bed. Home now, with funding to provide help for her family, she is speaking, walking, responsive, and hopeful once again.

Community Ties

Participants who have relocated to the community return to a natural support system (friends, neighbors, family, etc.) of some type. They generally do not rely solely on the COP or Waiver programs to provide all their support. Family members provide the most unpaid support to participants. Some participants rely on friends and others, such as fellow church members.

The existence of a supportive spouse can greatly enhance the relocation process. Table 5 describes the marital status of the participants. As would be expected with the high number of elders in the initiative, the largest group is those who are widowed. As some of the stories tell us, an older spouse may not be able to provide the level of support a frail or medically involved person needs. However, the existence of a spouse at home means, most importantly, that there is a home to which they can return.

Table 5
Participants by Marital Status (n=153)

Marital Status	Number	Percent
Married	31	20.3%
Divorced	35	22.9%
Widowed	53	34.6%
Separated	2	1.3%
Never Married	29	19.0%
Unknown/Other	3	2.0%

Behind the numbers…

¤ An 85-year-old woman fractured her hip and then suffered a stroke. Her husband was unable to provide all of the care that she needed, county COP and waiver funding were not available, and she was discharged from a hospital to a nursing home. She desperately missed her farm home of 55 years in Taylor County, her husband and her dog. She became apathetic and depressed. Always a very determined and independent person, she stopped working on her physical therapy when it appeared there was little chance of going home soon. She spent most of her time in her room sleeping. When relocation funds became available, she was eager to move and has made remarkable progress since she has been home. She receives help with her personal care and medications as well as with meals and chores.

Perhaps surprisingly, many participants have been able to maintain their networks despite their placements in nursing homes and relative isolation from their communities. These support networks are important for a relocated person to successfully remain in the community. Ties to the community can prevent a person from being as isolated at home as in a nursing home. The percentages shown in Table 6 are similar to those found in the COP/Waiver population.

Table 6
Participants by Natural Support Systems (n=153)

Natural Support	Number	Percent
Spouse	27	17.6%
Parent	9	5.9%
Adult Child	59	38.6%
Other Relative	18	11.8%
Non-relative	21	13.7%
No Primary Support	19	12.4%

Behind the numbers…

¤ At only 53, a man from a northeastern county was very dissatisfied while protectively placed and living in a nursing home. He did not like the food and had not been eating well. Along with a number of medical and health problems, he has a diagnosis of depression. He showed disruptive behaviors in the nursing home, attacked staff and other residents and threatened to burn the nursing home down. The police were called. His closest friend was consulted and believed the behavior was related to being in a nursing home. He began taking his friend on home visits. During those visits he was fine and only became upset when he knew he had to return to the nursing home. Finally, the friend agreed to have the man move into his home. This individual has been a loner all of his life and is relieved to have his privacy again. He works on the computer, is an avid reader, and has no more violent or disruptive behaviors at this time.

¤ Only 62, Mr. R. had worked as a cook in Madison area restaurants for 37 years until his first small stroke four years ago. Always a loner, he had lived in his apartment for many years. After his first stroke, he was not able to work full time any longer. Before long, he had several more strokes and was no longer able to work. With no savings, he lost his apartment and belongings and went to a nursing home for what looked like an indefinite future. After living alone for years, he was very unhappy living among large numbers of people and longed for his quiet apartment and familiar neighborhood. With the special relocation money, a county social worker was able to secure another apartment in the old neighborhood and even replace all the lost furnishings and supplies needed to make it a home. Mr. R. has an old friend, who is also very low income. The county recruited him with a small amount of money to take Mr. R. fishing or to attend neighborhood events together.

Living Arrangement

More than half of the participants moved to a home setting, either to their own home or apartment or to a relative's home. A significant percentage, however, moved to substitute care settings (almost 46 percent). By way of comparison, only about 12 percent of people in the overall COP/Waiver population live in these types of settings. Tables 7, 8, and 9 summarize the relocated participant's current living arrangement, the settings to which they moved upon relocation, and where they lived as of March 2002.

Table 7
Relocated Participants by Living Arrangement (n=147)

Living Arrangement	Number	Percent
Transitional Housing	1	0.7%
Living with immediate family with attendant care	3	2.0%
Living with immediate family	22	15.0%
Living with extended family with attendant care	1	0.7%
Living with extended family	1	0.7%
Living with others with attendant care	64	43.5%
Living with others	10	6.8%
Living alone with attendant care	3	2.0%
Living alone	42	28.6%

Behind the numbers…

¤ A 90-year-old woman in Green County was admitted to a nursing home for a short stay. Services were not available to help her return home. She became weak and depressed, developed a bedsore, and lost the ability to walk. In spite of these limitations, she began to work at getting herself out of the nursing home. Fiercely independent all of her life, she operated a tavern by herself for many years. She insisted she would leave whether or not funding and services became available. Luckily, the relocation funding was announced and this woman was able to move safely to her home with help with chores and bathing and with an emergency alert system.

¤ A different kind of story is that of a 73 year old man in south central Wisconsin whose family had always treated him as mentally retarded. They made fun of him and may have abused him. When some medical problems led to a nursing home stay, he blossomed. His health improved, and he loved the activities. He developed an interest in, and discovered he had a talent for, drawing and music. He likes the out of doors and was assisted to spend time there. After a total of nine years in the nursing home, somebody suggested he might like living more independently. There was a wait for funding, but when funds for relocations became available he was able to move to a small CBRF, away from his family. He continues to pursue new interests and opportunities with much more confidence and self-esteem than he used to have.

In some cases, a participant's living situation changed as his/her condition changed. Tables 8 and 9 summarize where participants lived upon relocation, and where they are living as of March 2002. The number of relocated participants who reside in their own home or apartment increased from 73 to 86.

Table 8
Relocated Participants by Immediate Post-Relocation Residence[6] (n=147)

Residence Type	Numbers	Percent
Adult Family Homes	27	18.4%
Community-Based Residential Facilities	40	27.2%
Home/Apt	73	49.7%
Residential Care Apt Complex	7	4.8%

[6] Adult Family Homes are residential settings for up to four individuals with long-term care needs. Community-Based Residential Facilities serve five or more individuals and range from small, home-like settings to large institution-like facilities. Residential Care Apartment Complexes consist of private living units with an array of services available to residents as needed or desired.

Table 9
Participants by Last Reported Residence (March 2002)

Residence Type	Number	Percent
Adult Family Homes	21	14.3%
Community-Based Residential Facilities	38	25.8%
Home/Apt	86	58.5%
Foster Home	2	1.4%

Of special interest is the creativity that some care managers showed in developing new homes for individuals. In some cases, the arrangements proved to be beneficial to more than the relocating nursing home resident and expanded the available housing and workforce.

Behind the numbers…

¤ In January of 2001, a 54-year-old woman in Washburn County experienced respiratory failure from pneumonia and was placed on a mechanical respirator. After a long hospitalization, she was admitted to a nursing home and faced a three to five year wait for COP or waiver funding to pay for the supports she would need to return home. In the meantime, her daughter with a developmental disability had been placed in a child foster home. At the same time, the social worker was working with another woman trying to get out of a seriously abusive situation with her husband. The situation was resolved and the husband was out of the picture. That woman was left with her home, but with no job, few job skills, and low self-esteem. The social worker arranged to have the home licensed both as a child foster home and as an adult family home, and the woman with the disability and her daughter moved in. One woman has an income and a meaningful new career, and the other woman and her child have a safe home with the supportive services they need.

Long-Term Care Experience

To receive funding from the COP Waiver, participants must meet nursing home level of care criteria. Most (74 percent) were rated at the skilled nursing facility (SNF) level. This is a considerably higher percentage than that found among the overall COP Waiver and CIP II population, where only 35 percent had an SNF rating (roughly 87 percent of people in nursing homes are at the SNF level). The second largest group are those whose level of care is unknown because it was not entered on the Medicaid nursing home billing system. The large number of relocated participants with SNF ratings indicates that the counties are serving people with complex medical needs.

Table 10
Participants by Level of Care[7] (n=153)

Level of Care	Number	Percent
SNF	113	73.9%
ICF 1	12	7.8%
ICF 2	2	1.3%
ISN	2	1.3%
DD 2	1	0.7%
Unknown	23	15.0%

Table 11
Participants by Time Spent in Nursing Home (n=125)

Time Spent in a Nursing Home Before Relocation	Total Number of People[8]	Elderly	PD	Other
1-2 mos.	20	12	5	3
3-4 mos.	34	21	9	4
5-6 mos.	18	9	8	1
7-9 mos.	12	7	2	3
10-12 mos.	8	1	4	3
1-2 years	11	3	4	4
Over 2 years	22	11	7	4
Total	125	64	39	22

Fifty-eight percent of the participants found in the Medicaid database were in the nursing home for six months or less. Twenty-seven percent were in a nursing home for more than a year.

Behind the numbers…

¤ Although only 58 years old, a man in Washburn County has lived in various institutional settings and nursing homes for the past 20 years. In the home where he lived most recently, all of the other residents were decades older than he was. The relocation funding allowed planning for a much more age appropriate life in the community. A specialized adult family home has been developed in the home of a man skilled in dealing with the mental health, physical, and medical challenges this individual presents.

[7] ICF = Intermediate Care Facility, SNF = Skilled Nursing Facility , ISN = Intensive Skilled Nursing (more specific and complex needs than SNF) and DD = Developmentally Disabled

[8] This information is from the Medicaid database (MMIS). Some individuals were in nursing homes under Medicare or a private insurer. They would not have nursing home information in the Medicaid system.

Table 12
Participants by Time on COP/Waivers (n=125)

Time on COP/Waivers after Relocation	Number of People	Elderly	PD	Other
1-2 mos.	36	16	13	7
3-4 mos.	32	15	12	5
5-6 mos.	40	25	8	7
7-9 mos.	17	8	6	3
Total	125	64	39	22

Most of the people started on the waivers in 2001, and the short time periods here reflect this. A follow-up study should provide more useful information.

Table 13 is a cross-tabulation of the above showing time spent in a nursing home by time spent on COP/Waivers.

Table 13
Cross-tabulation of Time Spent in Nursing Homes by Time on COP/Waivers after Relocation
(as of March 2002)

Time Spent in a Nursing Home Before Relocation	Time on COP/Waivers After Relocation				
	1-2 mos.	3-4 mos.	5-6 mos.	7-9 mos.	Total
1-2 mos.	6	1	8	5	20
3-4 mos.	8	12	10	4	34
5-6 mos.	7	2	7	2	18
7-9 mos.	3	4	2	3	12
10-12 mos.	3	2	3	0	8
1-2 years	4	5	2	0	11
Over 2 years	5	6	8	3	22
Total	36	32	40	17	125

Table 14 illustrates the number of relocated participants who have left the program. The only two reasons listed for case closure were death and return to a nursing home.

Table 14
Participants by Case Closure
(as of March 2002)

Reason for Case Closure	Number	Percent
Died	4	2.6%
Returned to Nursing Home	5	3.3%

Of the five people who returned to a nursing home, two had a serious change in condition that prevented them from being served in the community. One of them later died. Two others began showing increased signs of confusion, and their families convinced them to return to a nursing home. In both cases, the burden of care fell on one child, who decided he/she was unable to continue caring for his/her parent in the community. The fifth person had no community supports, and her family lived several hours away. Her condition also deteriorated and she returned to the nursing home. This person may have been successful in a more supportive community setting, such as a CBRF or an adult family home, but her family and her doctor convinced her to remain in the nursing home.

Cost Comparisons

Department staff conducted an analysis of the costs of relocated individuals while in a nursing home and when relocated to the community. All Medicaid and HSRS reportable long-term support costs, including acute and primary care, were included when determining the per diem cost in each given month. Some months were excluded from calculations because of ambiguities and other potentially misleading data (for example, partial or mixed months of care). Data on some individuals was insufficient or unclear and a nursing home/community care comparison could not be fairly determined. Although care was taken to use the best data possible, the conclusions are only tentative. In some cases, the average per diem for an individual is based on limited experience in a given setting.

Of the 153 people in the 2001 relocation initiative group (all persons for whom the Department started a relocation file, whether ultimately relocated or not), 86 (56 percent) had lower daily costs in the community than they had when they were in a nursing home. Forty (26 percent) had higher costs in the community than they had in a nursing home. For 27 (18 percent), the data available was unclear, inconclusive or not applicable. For example, an individual may not have had any "clean" months; that is, months in which they were clearly in one setting or the other. In addition, a small number of individuals were never actually relocated even though work was commenced to develop a relocation plan. Those individuals are not included in the following data.

Overall, daily community costs were almost 13 percent lower than nursing home costs. Daily costs in the two settings are summarized in the following tables.

Table 15
Per Day Cost Comparisons—Nursing Home & Community

	Nursing Home	Community
Low end of range	$ 49.77	$ 14.13
High end of range	$260.53	$352.14
Median (mid-point of range)	$101.35	$ 74.76
Average (mean)	$104.91	$ 91.58

Average daily costs in both settings varied significantly by the age of the participant. Individuals under age 65 had higher daily costs on average than did individuals age 65 and older.

Table 16
Per Day Cost Comparisons—By Age

Age	Nursing Home Average	Community Average
<65	$119.85	$118.30
65 +	$ 91.47	$ 72.80

Conclusion

While the Department has always encouraged and supported the relocation of individuals from nursing homes to the community, a federal Nursing Facility Transition grant received by the Department in 1999 provided a focus for increased activity. That federal grant, known as Homecoming, operated for fifteen months through 2000. It provided funds to cover one time relocation costs and enlisted the help of independent living centers to identify and assist persons who were interested in moving to the community. In an effort to keep up the momentum that was built under the Homecoming program, the COP Waiver funding described earlier in this report was set aside to enable more people to relocate in 2001.

In late September of 2001, the Department was awarded another Nursing Facility Transition grant. The grant was received in late September of 2001. While this new grant is slightly different from the original Homecoming grant, it will continue the mission of ensuring that people are able to live where they want. Counties are continuing to relocate individuals from nursing homes with the assistance of special funding that the Department has been able to identify outside of on-going county allocations. In 2002, 159 people were relocated under the auspices of Homecoming II. The new grant project will operate through September of 2004 with an overall goal of relocating 400 individuals.

Table 17
Summary of Relocation Activities with Special Funds

Project or Initiative	Year(s)	Number of Relocations
Homecoming I	1999-2000	81
2001 Relocation Initiative	2001	147
Homecoming II	2002	159

A future report will provide a similar analysis to that contained in this document of the people relocated with special funding in 2002 and will provide follow-up information on the people relocated in 2001. In addition, the Department will examine the outcomes of a group of people relocated from nursing homes as part of these special initiatives.

For additional information contact:

Gail Propsom
Department of Health and Family Services
Bureau of Aging and Long Term Care Resources
at
608/267-2455
or
propsgf@dhfs.state.wi.us